

UDC *Update*

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UDC Data Accepted for Presentations

Three abstracts using data from the Universal Data Collection Project (UDC) have been accepted for presentation at meetings that will be held later this year. Two abstracts were accepted for the World Federation of Hemophilia (WFH) World Congress meeting to be held May 21–25, 2006, in Vancouver, Canada. The first of these abstracts was submitted by a colleague of Dr. Nigel Key (member of the UDC Working Group), Dr. Aneel Ashrani, and describes rates and risk factors for joint infections in males with hemophilia. The study looked at data collected from participants who had least two visits during the period from 1999 through 2005. Of the 8,024 eligible participants, 24 had a joint infection reported in their medical record, and were defined as case patients. These case patients were compared with the remaining study participants for the following risk factors: age, race, hemophilia type and severity, number of joint bleeds, use of a central venous access device, presence of an inhibitor, at least one target joint, invasive procedures, and HIV and HCV infection. Of the risk factors assessed, only age, black race, presence of an inhibitor, having an invasive procedure in the past year, and presence of at least one target joint were found to be independently associated with a joint infection. The investigators concluded that joint infections are not common among people with hemophilia, and it is more likely to occur in conjunction with underlying arthritis and a history of recent invasive procedures.

The second abstract accepted by the WHF was submitted by Mike Soucie, PhD. and describes the initial data collected in UDC on children younger than 2 years of age. Descriptive data on enrollment, disease type and severity, demographics, reason for diagnostic testing, age at first diagnosis, method of delivery, bleeding and treatment were highlighted in the abstract.

A third abstract, submitted by Dr. Roshni Kulkarni (member of the UDC Working Group), describing hemophilia complications and bleeding episodes in the UDC population younger than 2 years of age, was accepted for oral presentation at the Pediatric Academic Societies meeting April 29–May 2, 2006, in San Francisco, California. The abstract focused on the sites, causes and complications of bleeding in this age group which were distinct from the adult population.



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Intracranial hemorrhages, inhibitors and neurological deficits were also described. Trauma was found to be a major cause of bleeding and spontaneous joint hemorrhaging was rare.

These are some excellent examples of how the data collected in the UDC are being used to educate clinicians and researchers around the world about the complications of bleeding disorders in various populations. Hopefully these data can help those working in the field better serve those participating in the UDC project.

Lab Tracker Update

The UDC sites are making progress with instituting Lab Tracker, the electronic clinical data collection tool that has been adopted by the hemophilia treatment center network. So far, 53 sites have begun to submit their UDC data electronically. The Lab Tracker onscreen data validation during data entry feature will make these validation error reports a thing of the past. Thanks for all your continued hard work in making electronic UDC data collection a reality!

Quality of Life Questionnaire- Reminder

For those centers where quality-of-life (QOL) data collection is underway, a quick reminder — please don't forget to write a **CDC ID number and date of visit** on the QOL form before giving it to each patient. This is important because the patient will complete the form and immediately seal it in an envelope. If there is no identification on the form, the data for that patient could potentially be lost. Thanks for your cooperation on this issue!

If you have any questions about the QOL aspect of the UDC, please contact Vanessa Byams at 404-498-2723, or by e-mail at ver0@cdc.gov.

UDC Working Group

On January 9–10, 2006, the UDC Working Group met in Atlanta, Georgia. The purpose of the meeting was to allow group members an opportunity to review the progress of enrollment and the

data being collected in the UDC project, advise on possible additions to data collection activities, and provide feedback to CDC about the progress of UDC efforts in the group members' institutions or regions.

The group also discussed creating an official, transparent procedure for UDC Working Group member selection and rotation, and continued work on a document that provides guidelines for submitting research proposals that use UDC data to answer important clinical questions. Both documents are in the works and will be forthcoming within the next 2 months.

Vacancy in the UDC Working Group

The Working Group for the UDC project is seeking a data coordinator representative. As the hemophilia treatment center (HTC) network develops and adopts the Lab Tracker clinical software tool, it is expected that there will be an increased role for data coordination in the treatment centers to manage the clinical data entered and stored in these systems; therefore, the UDC Working Group considers it important to get feedback and add the perspective of data coordinators to the group as the UDC project continues to grow.

Following is a list of the qualifications for the data coordinator representative:

- Is employed at a federally funded HTC
- Has in-depth knowledge of UDC data collection
- Works at an HTC that has maintained high levels of participation in the UDC project
- Has experience in managing data related to the UDC project
- Has played a role in the integration of UDC into the HTC daily clinic workflow
- Has experience with UDC data collection using Lab Tracker
- Has an awareness of efforts to develop a national research database

While not required, education or training in database

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management and an understanding of Web-based data applications is desirable.

If you are interested, submit a letter or email to your Regional Coordinator that includes a paragraph or two describing your qualifications and a current resume or CV.

For more information about the UDC Working Group please call Mike Soucie at 404-498-2753.

Data Entry Corner

Validation Errors

We appreciate your efforts to help ensure that the UDC database is current and we are continuing to catch up on the corrections for 2005's validation reports. At this time, we are asking that anyone who has outstanding validation reports from 2005 to please fax them in (404-498-2750 or 404-498-2740) as soon as possible. As a reminder, we will send the centers with outstanding validation errors requests for corrections until their data are current.

UDC Staff

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